

Paying Family Caregivers

to Provide Necessary Supports to People with Intellectual and Developmental Disabilities

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Introduction

Some people with disabilities use direct care workers, including [direct support professionals \(DSPs\)](#), to help them with day-to-day tasks such as eating, bathing, and engaging in the community. These support services are often covered by Medicaid through a DSP agency.

Unfortunately, there is [currently a significant shortage of DSPs](#). In a 2023 survey of provider organizations, [95 percent](#) indicated they had experienced moderate or severe staffing shortages in the past year. This means that many people are forced to go with less support than they need, make hard choices about what type of activities they will use available support for, and in some cases, go without any support at all. Direct support is critical to the health and wellbeing of many people with disabilities, as well as providing needed access to the community.

In addition to concerns about the health and wellbeing of people with intellectual and developmental disabilities (IDD), the shortage of direct care workers leads to [significant concerns for the family members](#) providing care. Nearly half of family caregivers have experienced at least an adverse economic impact from caregiving, and nearly two-thirds have had employment impacts.

One way to mitigate the significant [health and economic challenges](#) that come with the shortage of DSPs is to **pay family members to provide support**. Many family members already step in to perform this support. The estimated value of unpaid **labor provided by family caregivers amounts to [\\$600 billion annually](#)**.

This paper discusses the options states have for allowing paid family caregiving in Medicaid and some of the challenges.

Can Medicaid Pay Family Caregivers for Services?

Maybe. Each state's Medicaid program is different and therefore has different services and policies, which are all bound by federal restrictions. Ultimately, in most cases [it is the state's choice](#) to allow paid family caregivers. Even in the cases where a state *could* allow paid family caregivers, it does not mean they *have* to do so.

During the COVID-19 pandemic, many states [changed their policies temporarily](#) to allow family members to be paid caregivers. The public health emergency triggered certain flexibilities that allowed states to easily put temporary policies in place, including allowing practices that would not be typically allowed. Post-pandemic, many states continued the paying family caregiver policies, [while some did not](#).

What Medicaid Services May Family Caregivers be Paid to Provide?

Understanding if your state can pay family caregivers to provide a Medicaid service can be complicated and require some level of Medicaid knowledge about how services are provided. The most common service family caregivers provide is personal care, or assistance with activities of daily living (ADL), which is the focus of this paper.

Medicaid can cover personal care services to support ADLs through multiple mechanisms, some of which allow family members to be paid to perform services, and some of which do not. Under a simplified analysis, the key distinction is *whether or not the service is a "state plan personal care service."* States may call the service different names, like personal care assistance, and may offer a similar sounding service through different programs. Although there are some other variables, the simplest way to analyze whether the state can choose to allow family caregivers is to first find out whether the service is state plan personal care services, or if it is something else, like through an HCBS waiver or other mechanism.¹

¹ For example, a state may offer state plan personal care services to all those on Medicaid who qualify for it, but also offer a very similar service, even under a similar name, through a 1915(c) waiver or other Medicaid mechanisms. Many people know a 1915(c) waiver by its name in a given state, like the Innovations Waiver in North Carolina for those with I/DD, or by a shorthand as just an HCBS waiver. To make things even more complicated, some states run all or part of their Medicaid program through Section 1115 demonstration programs, which may allow other

State Plan Services

Most Medicaid services are “state plan” services. In its state plan, a Medicaid agency describes how it will provide mandatory Medicaid services and any additional optional services.

Under state plans, the Medicaid agency provides many different kinds of services, one of which may be personal care services. Unfortunately, when offered through a state plan, most family members are not allowed to be paid to provide these services, because of restrictions in the Medicaid statute.²

States also provide home health services through the Medicaid state plan. Home health services typically cover higher skilled services, such as nursing. Home health does not have the same restrictions around paying family caregivers as personal care. Therefore, states may allow payment of family members to provide home health services if they meet the qualifications as a provider.

States may have other state plan services that allow paid family caregivers, often through [home and community-based programs](#).

Can I/My Family Member be Paid to Provide Care?

Is the service under the Medicaid State Plan?

Yes

No

State Plan Service What type of service?

→ **Personal Care**
A family member likely CANNOT be paid to provide this service

→ **Home Health**
A family member MAY BE able to be paid to provide this service

Non-State Plan Service

→ **HCBS Waiver**
A family member MAY BE able to be paid to provide this service

Each state's Medicaid program is different and has different services and policies. Ultimately, it is the state's choice to allow paid family caregivers.

Non-State Plan Services

A state may also have other services, such as those that are provided through a waiver program, like Section 1915(c) home and community-based waiver programs. These are commonly referred to as “HCBS waivers” or “1915(c) waivers”, or by the state name for the

features, and have other names for their HCBS programs within that program, like Employment and Community First Choices in Tennessee.

² The Medicaid regulations define this restriction, “legally responsible relatives” may not be paid to provide state plan personal care services. “Legally responsible relative” is defined as spouses and parents of minor recipients, including stepparents who are legally responsible for minor children.

program like the IRIS program in Wisconsin. Under these waivers, states may target a specific population, such as people with intellectual and/or developmental disabilities, design a set of services for that population, and limit the number of people enrolled in the waiver at any given time.³ States have a great deal of flexibility in defining 1915(c) waiver services and who may provide each of them. Part of this flexibility is the option to allow paid family caregivers, for both personal-care-like services under the waiver and other waiver services.

States fill out waiver applications that are then approved by the federal Medicaid agency, the Centers for Medicare & Medicaid services. The final approved documents are [available publicly](#). In these applications, states must indicate whether they allow paid family caregivers and for what services.⁴ The state must also describe other restrictions it has opted to put on paying family caregivers. These can include hour and time-period limitations, that family members may only be paid when there are no other providers available, and if there are different rules for people who are self-directing their services.⁵

Issues to Consider Regarding Paying Family Caregivers

Why Allow Paid Family Caregivers?

There are several arguments for allowing family members to be paid as caregivers.

To ensure availability of care. DSP turnover [can decrease quality of life and increase health and safety issues](#).

To respect individual choice. A central concept of HCBS is that the choice of the individual with a disability is prioritized. People who receive HCBS may prefer that a

³ The limited nature of these waiver programs often creates waitlists of people trying to get onto the waiver. Therefore, a person may be receiving state plan personal care services and not be allowed to use paid family caregiving, but once enrolled in the waiver, begin paying family members. However, in many states, [waiver waitlists are years long](#).

⁴ Waiver personal care services are only supposed to be provided when they are services that a legally responsible person, such as a parent of a minor child, would not ordinarily perform in the household on behalf of a similarly aged person without a disability or chronic health condition. The service must also be necessary for the health and welfare of the individual with a disability, and to avoid institutionalization. States must make other assurances about best interests of the individual and health and safety protections.

⁵ Self-direction may take a couple of different forms, but it generally includes individuals hiring caregivers directly rather than through an agency. When a state selects this option, it may allow those who self-direct more flexibility on hiring family members than allowed under the waiver for those using agency services.

family caregiver be paid to provide their care rather than a worker from an agency. This may be due to:

- Greater comfort because the family caregiver knows their needs;
- Ability to use their service hours in a way that works better for their schedule;
- Increased reliability; and
- Greater household financial stability. If DSPs are not available, family members may need to take off work to provide care, which can lead to unstable employment.

Why Not Allow Paid Family Caregivers?

A state's decision on whether to allow paid family caregivers is often based on a variety of reasons, and this paper covers a few frequently cited by states. Your state's reasons may be different.

Caregiver Burnout: One of the most common reasons states cite is concerns about caregiver burnout. Policymakers often say they do not want family members who provide unpaid supports to also be the ones providing the paid supports because then they are at higher risk of burnout based on how much support they are regularly providing. This argument assumes that agency providers are available and individuals would otherwise be receiving paid care from non-family members. In this era of provider shortages in many areas, the only realistic option for some people is paying family members. To address this burnout concern, many states that allow paid family caregivers set weekly limits on hours a family member can work.

Conflicts of Interest: States also frequently say they are protecting against conflicts of interests. This conflict occurs if the paid family caregiver is also the legal guardian, and the choice to hire themselves may be self-interested rather than the choice the individual receiving care would have made. States may also say they do not allow paid family caregivers to protect individual choice and independence of a person with a disability.

Protecting Individual Choice: A central idea in HCBS is that individual choice should drive the services that are provided and how they are provided. For some people, paying family caregivers would not be their preference due to privacy, independence, and dignity of risk (the right to take reasonable risks even if there are negative consequences). An individual who is receiving services should always be able to choose among an array of trained service providers for each of their services and should not need to rely on paid family caregivers. The current reality is that sometimes

family caregivers are the only available option, so paying them for that support helps ensure individuals receive their services.

States also frequently cite other concerns. For example, that decreasing the number of people providing supports to an individual may create the isolation and lack of oversight that makes it difficult to identify abuse and neglect. States may also have licensure rules, such as who may provide nursing or nursing assistant services, that would prohibit unlicensed family members from being paid to provide certain types of support; this is especially true for nursing services.

Paying Family Caregivers May Affect Medicaid Eligibility

It is important to note that paying family caregivers in the same household may affect Medicaid eligibility of people in that household. This is because it increases income, which is typically part of Medicaid eligibility criteria. States are generally supposed to consider whether paying for family caregivers will affect the eligibility of the person being cared for to continue receiving services. Importantly, payments for providing [Medicaid HCBS services are supposed to be treated as “difficulty of care” payments under IRS rules](#) and not be counted towards income for Medicaid eligibility purposes for certain categories of eligibility. However, these income counting rules are not always properly followed, so families should make sure they understand the impact of paying family caregivers on the Medicaid eligibility of all household members.

Conclusion

Paying family caregivers can be an important way to make sure people with direct support needs receive the Medicaid services they need. The question is whether states are willing to do so, and under what circumstances.

Families and other stakeholders who want to change their state’s policies regarding allowing paid family caregiving should be able to help develop policies that would help address state concerns or otherwise identify solutions that will work to for individuals, families, and states so that services are available for those who need them. For more information on some of the policy considerations and Medicaid requirements, see the National Health Law Program’s paper on [Paying Family Caregivers: State Options, Limitations, and Policy Considerations](#).